

ETHICAL ASPECTS OF CLASHING TITANS: TRAUMATIC BRAIN INJURY VERSUS AUTONOMY

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REZUMAT. Aspecte etice privind autonomia pacienților cu leziuni traumatice cerebrale. Leziunile traumatice cerebrale (LTC) au devenit o cauza importantă de mortalitate și morbiditate atât în cadrul populației civile cât și celei militare, fiind considerate o adevărată epidemie silențioasă, mai ales ca incidența lor reală este în continuă creștere. LTC pot afecta capacitățile cognitive esențiale în exercitarea autonomiei individului. O caracteristică a acestei entități patologice este aceea că pacienții pot prezenta capacități intelectuale normale, aproape normale sau de limită, fiind însă în același timp certificați ca și competenți psihic și neavând nevoie de un tutore legal, chiar dacă s-a observat că o capacitate scăzută de a-și evalua propriile comportamente și limite este des întâlnită. Pentru a demonstra caracteristica anterioară am elaborat un chestionar care să reflecte constanța de sine, pe care l-am înaintat atât pacienților cât și aparținătorilor lor. Acest studiu a fost adresat unei populații recunoscute ca fiind cu risc crescut de a dezvolta LTC și anume copii, bătrani, indivizi cu status economic scăzut, persoane necasătorite precum și pacienți cu un istoric anterior de LTC sau boli psihice, distribuția pe sexe fiind egală. Rezultatele au arătat o diferență de opinii între percepția pacienților și a aparținătorilor. În astfel de cazuri, conservarea dreptului autonomiei nu este atât de clară cum s-ar crede în mod obișnuit, în consecință fiind nevoie de aplicarea unor comportamente și tactici etice particulare. O privire atentă asupra patologiei LTC și a consecințelor sale neurocognitive poate conferi o mai bună înțelegere a situațiilor care declină autonomia individuală cu păstrarea drepturilor legale și respectiv a conflictelor etice care decurg din aceasta.

Cuvinte cheie: *autonomie, leziuni traumatice cerebrale, comportament neurocognitiv, drepturi legale.*

ABSTRACT. Traumatic brain injury has become a leading cause of mortality and morbidity in both civilians and military, considered the modern version of a silent epidemic, since its real incidence is on the rise. In the field of medical ethics, "autonomy" represents endogenous determination that does not withstand

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controlling interferences not personal limitations. Traumatic brain injury (TBI) might affect cognitive capacities critical to the adequate exercise of autonomy. The hallmark of this disorder is the possibility of producing survivors who preserve normal, almost-normal or border-line intellectual capacities, certified as being competent and not in the need of a guardian or substitute decision maker, even though an impaired capacity to evaluate their own behaviors and limitations accurately is widely encountered. Aiming to reflect the proposed pattern, a questionnaire echoing self-awareness was appraised by patient and associated family member. The study revealed population at risk for TBI resembling childhood age, elderly, low-income individuals, unmarried people and patients with previous history of TBI or psychiatric pathology, with equal sex ratio distribution. Moreover, a difference of opinions has been noticed when evaluating the arisen topics from the questionnaire. In such cases, conserving the right of autonomy is not such as forthright as one might consider, thus requiring different ethical commitments and tactics. A slight look inside the neurologic pathology of TBI and its neurocognitive consequences seems to yield the basics of understanding situations that decline autonomy with preserved legal rights.

Key words: *autonomy, traumatic brain injury, neurocognitive behavior, legal rights.*

Introduction

In a defiance of the high media coverage and awareness, traumatic brain injury (TBI) is still representing one of the most important leading causes of mortality and morbidity in adults [1], encompassing different social backgrounds, ages and genders [1]. It is characterized by injuries that range from scarce to serious, causing long term disability regarding cognitive behavior. Since the dawn of science, medical ethics has concerned itself with balancing the patient's best interest (both psychological, social and medical) with legal rights and autonomy. As encountered in modern day cultures, these notions are complementary at times and clashing at others. Autonomy has its origins in ancient Greek assembling "autos" and "nomos" [2] with current meaning of "self", respectively, "law", pointing out self-governance as the central conception [3]. From medical point of view, it is considered that any legally competent adult is granted the option of own treatment decisions and outstanding this options have ethical, as well as legal constraints that need to be further assessed [4]. A chosen path of treatment without prior consent, physical and psychological duress are just two examples of medical activities that are not ethically accepted, yet at times are chosen paths of treatment for the patient's best interest. As a consequence, the ethical framework that should guide the actions of medical personnel in their

interactions with these patients is not always straightforward and is worth examining more closely. Neuropathology of TBI seconding the neurocognitive changes seems to be the mile stone in understanding situations that decline autonomy with preserved legal rights [5].

Neuropathology and Neurocognitive Behavior of Traumatic Brain Injury

Despite the high number of studies conducted on this area, the precise pathological mechanisms that tie repetitive or single TBI to abnormal protein accumulation and neurodegeneration are not known entirely [6]. So far, it is a consensus that the initial event taking place in head trauma is mechanical distortion of brain tissue [7]. This is being caused by applying inertial forces upon the axons located in the brain, such as acceleration followed by deceleration. During acute traumatic brain injury, the brain and other components of central nervous system undergo shear deformation producing a transient elongation that selectively injures axons, small blood vessels, and astrocytes [5]. As a suitable scenario one could consider the following schemes: blunt force trauma applied to the cranial surface, vehicle accidents, close contact sports, etc. The sum of injuries is proportional to the severity, intensity and extent of applied force. In the last century, most animal studies regarding single or repetitive head trauma concluded that the initial abnormality of TBI happens due to mechanoporation [8]. Mechanoporation consists of a traumatic defect in the neuronal membrane that occurs at the lipid bilayer of the cell. As a result, various ions can move rapidly into or out of the cell following their pre-injury concentration; potassium moves outside while sodium, chloride and calcium enters the cell. Increased intracellular calcium may stimulate the release of reactive oxygen species (ROS) for mitochondria causing cell membrane and blood vessels destruction leading to diffuse axonal injury, ischemia, neuronal deficits and cell death. The outcome of axonal injury can vary from axotomy (irreversible axonal injury), alterations of electrophysiological function to neurotransmitters concentrations, both acute and chronically [8].

Regarding neurocognitive domain, pathological changes described previously affect the power and executive functions [9]. These impairments are secondary to the diffuse axonal stray inefficiency and contrast the preserved perceptual, motor and intellectual functions [5]. Alterations of basic mental functions are a common symptom registered after TBI relating to mental engagement in current cognitive duty, regardless its nature [8]. Disturbance occurs in arousal (diagnosed first; fastest recovery) and channel capacity (persistent) [10]. This disturbance is characterized clinically by difficulties in

three important domains: processing speed, multitasking, and cognitive endurance [11]. Slowed thinking process can be observed in all types of patients recovering from traumatic brain injury [12]. The multitasking reflects as the patient's impossibility to use the complex systems needed for memory and attention while applying external stimuli. Symptomatic TBI patients are often simply unable to sustain any cognitive effort for as long as they did prior to the injury [12]. Related to the reduction in cognitive endurance, patient complains that life in general, and cognitive tasks in particular, require more effort than used to. Furthermore, anticipating, goal selection, planning, initiation, sequencing, monitoring and correcting functions are disturbed [12]. The tasks mentioned previously are key components of the executive functions which give coherence to the human action. The importance of these is based upon one's capacity to accurately assess a given task. The deficit itself varies upon the affected lobe: for traumas occurring in the parietal side of the brain the patients cannot perceive their pathology, contrasting to frontal cases where is seen the loss of capacity to incorporate actual deficit into the global state of disease [11]. In conclusion, autonomy might be perceived as being compromised in both settings, but the underlying brain mechanisms are different leading to different tactics of bioethics appliance.

Material and Methods

The study group consists of 17 patients with a positive diagnosis of traumatic brain injury and conclusive markers of cognition disorder, both aspects determined priory to the examination. Patients were appointed to the Medical Legal Institute of Cluj-Napoca, Romania, during 2011-2015. Inclusion criteria rested on positive history of traumatic brain injury and relevant cognition disorder. Interviews regarding the patient's issues were pursued in a quiet yet comfortable place with the sole purpose of diminishing all possible interferences. The examination was conducted by a forensic doctor accompanied by a neurologist with high numbered years of clinical experience. During the exploration, the patients were asked to fulfill the specific questionnaire by grading questions with the self-opinion regarding arisen topics. The patient's form is similar to the one depicted below in Figure 2. Seconding the patients, a close family member or surrogate decision maker was interviewed by the same method. The survey attributed to the patient's family or tutor is depicted in Figure 3. Both patient and family were blinded from results of the test. Data resulted from both examinations underwent further analysis as depicted in the "Results" segment.

**Self-guidance Survey
Family/Significant Other Form**

Name: _____ Relationship to patient: _____

Patient: _____ Patient # _____ Date: _____

1	2	3	4	5
much worse	a little worse	about the same	a little better	much better

1. Did the patient's ability to live autonomously differ nowadays opposing prior to injury?
2. Do you notice any difference in financial managing of the patient nowadays opposing prior to injury?
3. Does the patient maintain easily interpersonal relationships with people the same he/she used to, nowadays opposing prior to injury?
4. Did you notice any difference in patient's capacity of sustaining tests regarding thinking and memory capacities opposing prior the injury?
5. Do you notice any difference in the patient's way of performing the acts he/she intends nowadays opposing prior to injury?
6. Do you notice any difference in the patient's vision acuteness nowadays opposing prior to injury?
7. Do you notice any difference in the patient's hearing acuteness nowadays opposing prior to injury?
8. Do you notice any difference in the patient's motor skills (arm and legs movements) nowadays since prior the injury ?
9. Do you notice any difference in the patient's coordination nowadays opposing prior to injury?
10. Do you notice any difference in the patient's capacity to acknowledge time intervals (date/month / year) nowadays opposing prior to injury?
11. Do you notice any difference in the patient's capacity to concentrate while performing a given task nowadays opposing prior to injury?

12. Do you notice any difference in the patient's emotional management towards friends/family or acquaintances, nowadays opposing prior to injury?
13. Do you notice any difference in the patient's ability to recall recent memories nowadays opposing prior to injury?
14. Do you notice any difference in the patient's planning skills nowadays opposing prior to injury?
15. Do you notice any difference in the patient's organization skills nowadays opposing prior to injury?
16. Do you notice any difference in the patient's ability to maintain emotional control nowadays opposing prior to injury?
17. How well adjusted emotionally is the patient now as compared to before his/ her injury?

Figure 3. Questionnaire provided to the patient's family member or substitute decision maker: In order to highlight the family members' opinions and reflections towards their relatives' disease while taking under analysis various tasks that encompass cognition evaluation.

Results

Data gathered in a Microsoft Excel sheet containing age, sex, question's number and graded form of both parts has been taken under analysis. The study groups were homogeneously composed, encompassing both female (n=8) and male sex (n=9) with a mean age of 48.7 years old with a standard deviation of 9.1 % years old. Results of our study concluded that men are as likely to undergo TBI as women. The ratio becomes equal when approaching fifth or sixth decade of life, due to increased risk of falling or associated pathology such as gait control, nervous system disturbances and low density of bone structure. Furthermore, the study revealed population at risk for TBI resembling childhood age, elderly, low-income individuals, unmarried people and patients with previous history of TBI or psychiatric pathology. Moreover, a difference of opinions has been noticed when evaluating the arisen topics from the questionnaire. To compress all the information gathered from questionnaires a chart comparing answers from family and patient was created, such as seen in Figure 4.

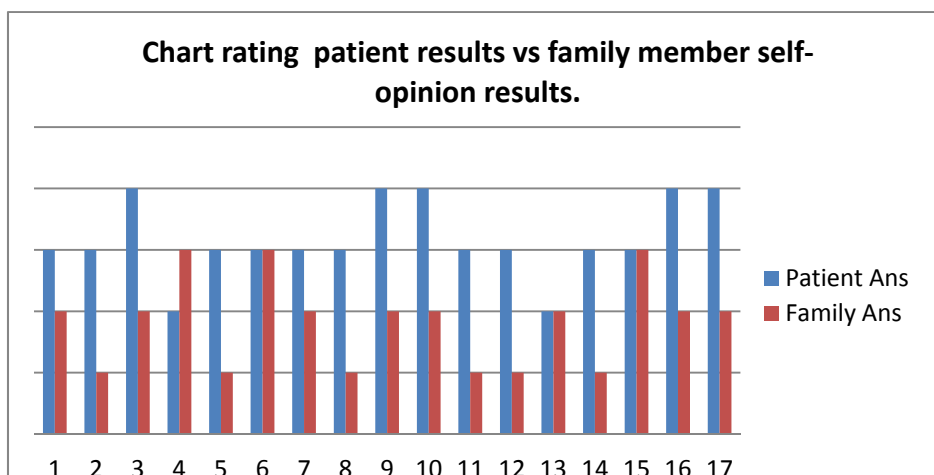


Figure 4. Chart rating the answers of both patient and family member: The chart highlights a visible contrast between the patient self-awareness and the opinion of the family regarding autonomous life of patient. The numbers below the chart represent the number of question analysed.

Ethical Aspects

According to the Joint Centre for Bioethics [13, 14] capacity is defined by “the ability to understand information relevant to a decision and to appreciate the reasonably foreseeable consequences of a decision“. As stated previously, patients with TBI preserve a high part of their prior-injury capacities, which clears them as entitled to own decisions, even though the make-of process is compromised. Therefore ethical issues arise, since a conflict appears between competing values. From a clinician stand point one question speaks louder: should it be taken as granted a patient’s TBI decision concerning choice of treatment?

It has been scientifically agreed that even small amounts of trauma occurring over short periods of time produce small deficits that are not easily depicted by modern imaging techniques. Those small shortfalls are not subject to quantification in routine medical practice. Scarce impairments to the frontal lobe results in difficulty of judgment, planning, inhibition, cognitive rigidity, lack of initiative or problems maintaining goal orientation over a long period of time. Emotional flattening or blunting and dulled emotional expressivity is also common when trauma occurs to the frontal lobe [15]. Additionally, small injuries to the temporal lobes causes memory decline, as a result patients have difficulties in retaining, withholding or sharing correct information. Conjointly, the temporal lobes form a part of the limbic system, thus providing emotional symptoms, both understanding and output, causing emotional flooding. The symptoms grow even bigger if there is involvement of the cingulate gyrus that has its main purpose of

regulating emotions. A peculiar aspect of injury to this level is the loss of orienting reflex. With small amount damage to the cingulate gyrus habituation to a new stimulus does not occur, hence the individual remains easily distracted by even a constant stimulus in his/her environment [15].

Another fragile to trauma structure is the corpus callosum. Its damage leads to alexithymia. This consists of difficulty identifying and describing the nature of one's own emotional being. Head injured individuals commonly have great difficulty talking about their emotions [15]. All in all, a clean bill of health seconding head trauma may be just a ticking bomb impacting the patient's daily routine, best evaluated by with close family members. The issue arises in the objectivity of relatives.

Besides clinical risk factors, there are aspects that cannot be controlled by an outside force, such as sex, race or age. Scientific based literature [16] has shown that the most prone to traumatic head injury is the pediatric consisting of infants or toddlers aged 4 years old. Second place is granted to the older adolescents aged 15-19 years old. The mature population follows the trimodal distribution with a trend toward trauma in adolescent life followed by decreased risk during adulthood. The prospect of trauma increases with passing time due to gait posture control or associated pathologies. What's more, for every age and race studied males are more prone to accidents than women. Genetic susceptibility and addictions (especially alcohol related) developing in a feeble patient may increase raise the number.

Alongside, the cognitive reserve theory may also play a role in the clinical set-up. It has been stated that a higher cognitive reserve might respond and compensate better, earlier and faster than a meager one [17].

Seconding the first "hit", emerge issues in determining the future medical and lifetime needs of this group of patients. These questions come to withstand the principle accurately stated by Justin Cardozo regarding the self-governance of a patient: "every human being of adult years and sound mind has a right to determine what shall be done with his own body" (Schloendorff 1914) [18]. Moreover, there are extensive models of recovery after brain traumatic injury; one patient might overcome medical expectancy, while others might be entrapped in Vegetative State during life-span. Trying to solve the ethical maze, another topic troubles waters; the fluctuation of "self" intervals during therapeutic treatment and recovery. Given these situations, medical experts should provide extreme cautions when assessing patient's recovery chances, keeping in mind that personal awareness of the victim is the key point in this decision.

The modern medical practice changed a lot throughout the last decade. Starting with an authoritarian model (the current physician withheld the power to decide course of treatment without prior consent of patient [19]), and reaching, nowadays, to more synergetic doctor-patient communication stipulated by the 2005 version of the WMA "Declaration on the Rights of the Patient" [4] which permits patients to choose proceeding doctor and path of treatment.

Medicine and Law supports competent patients to legal right of autonomy when deciding the preferred course of treatment [4]. Without compromised legal rights all doctors share information with patients in order to augment therapeutic outcome [4]. The dilemma surfacing, regards the patient's ability to fully understand the given situation hence the cognitive process that leads to a decision as being broken. The legal system demands, as one of its fundamental requisites, mental competence. As noted by the scientific literature, being competent depends upon minimal mental, including behavioral and cognitive state, in order to perform certain task that withstands actual civil and criminal law. It is also rendered as a physiological step up in therapeutic formulas for victim's family to seek medical advice and further counseling.

The main question surfacing refers to the exact moment of attributing a decision-maker surrogate. Who should be the appointed guardian? A family member, an outsider - objective member or should it be respected the patient's decision of guardian prior to injury? These questions bare more weight when dealing with patients trapped in vegetative state, as faced the decision to stop or not medical treatment, despite enormous costs and low life quality of the patient. One significant area of debate in VS cases is often whether or not a patient should be made a "DNR" (do not resuscitate) and if so, when. Both scientific and moral arguments have been stated on the ethical differences between withholding versus withdrawing care. To date, noting that withdrawing care reaches a greater level of potential moral and ethical compromise than that of withholding care.

Another ethical clash concerning TBI also comes from the patients' lack of autonomy. Thus, within the judicial system there has been observed that whenever it comes to the possibility of obtaining patrimonial gains, the manufacture and pathological exaggeration of symptoms had been frequently reported in the literature [20]. This is also the case of post-traumatic cognitive disorders. The thorny question that the forensic medical expert is bound to give an answer to, is whether between the incriminated traumatic brain injury, single or repeated and the cognitive disorders might exist or not a link of causality. The answer to this question inevitably gives rise to numerous ethical difficulties of whose right interpretation basically depends the correct forensic evaluation of the case. The ethical difficulties start in most cases from the patient's attitude and that of his caregivers. From their point of view, the acceptance that between the cognitive disorders and the previous brain trauma there would be no connection, is extremely difficult to understand.

From this subjective reasoning start several attempts of simulation or exaggeration of symptoms in order to obtain unjustified monetary benefits. The evaluation of this apparent causality link involves working with a neurologist, the latter being the one who has the power to establish the diagnosis of cognitive disorders. But establishing the existence of a causality link between trauma and the later cognitive disorders burden, lies with the forensic medical expert. Moreover,

due to the fact that between the time of occurrence of the cognitive disorders and the traumatic brain injuries a very long period of time had passed, ranging from years to even decades, the assessment of this connection becomes very problematic.

Another distinct and extremely important ethical aspect comes from the way in which the patient's information obtained by the two categories of doctors, physician (neurologist) and forensic medical expert is being used. Up to a point the two assessments are common and overlap. However, since the beginning stands out the distinction between the two types of relationships: in the neurologist's case it is a classic doctor-patient relationship, this implying the obligation of confidentiality. Whereas in the forensic medical expert's case, the obligation of confidentiality cannot be guaranteed, because in many cases the employer of the later is a third party, such as prosecutor, lawyer or even the perpetrator that provoked the traumatic brain injury in the first place.

Discussion & Conclusion

The discrepancy between responses in patients and family members bears in high percentage a scientific explanation regarded to be caused mostly by side effect from the repetitive traumatic brain trauma resulting in diffuse axonal injury, thus risking the integrity of white matter tracts with endangerments of the brain network connection. Additionally, secondary cellular injury mechanisms occurs leading to synaptic dysfunction, cell death and axonal degeneration that are not always picked up by imaging techniques, but they are given out by the patient's reaction to different topics. Likewise, in the whole set-up of a TBI patient it plays an important role the amount, the duration, location of the cerebral traumatic event and most important the patient itself, since its particular features represent circumstances to a better or worst prognostic.

Patients diagnosed with TBI possess complex and various clashes in evaluating competence, since it cannot be clearly determined by scientific methods. Further studies should be performed in order to assess if a person could be rendered as capable or not in pursuing any type of required tasks. To sum all up, there have been numerous studies conducted including debates regarding "for/against" moral arguments, yet no substantial responses nor consensus criteria have been brought to scientific practice. As a final conclusion, ethical dilemmas regarding this topic are hardly solvable to the full satisfaction of all members involved in caregiving.

Disclosure of Interest. The authors declare that they do not have any competing interests.

Abbreviations. TBI - traumatic brain injury; ROS - reactive oxygen species; LTP - impaired long-term potentiation; LTD - long-term depression; VS - Vegetative State; DNR - do not resuscitate.

REFERENCES

- Faul M, Xu L, Wald MM, Coronado VG. Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths 2002-2006. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2010.
- Lux WE. The neurocognitive basis of compromised autonomy after traumatic brain injury: Clinical and Ethical Considerations. *Neurotherapeutics*. 2007 Jul;4(3):525-30.
- Frankfurt HG. Autonomy, necessity, and love. In: *Necessity, volition, and love*. Cambridge: Cambridge University Press; 1999: 129–141.
- The world medical association, inc. World Medical Association declaration of Lisbon on the rights of the patient, October 2005, page 2-3.
- Love S, Louis ND, Ellison WD. *Greenfield's Neuropathology*, 8th edition. Hodder Arnold, London, UK, 2008.
- McKee AC, Stern RA, Nowinski CJ, Stein TD, Alvarez VE, Daneshvar DH, Lee HS, Wojtowicz SM, Hall G, Baugh CM, Riley DO, Kubilus CA, Cormier KA, Jacobs MA, Martin BR, Abraham CR, Ikezu T, Reichard RR, Wolozin BL, Budson AE, Goldstein LE, Kowall NW, Cantu RC. The spectrum of disease in chronic traumatic encephalopathy. *Brain*. 2013 Jan; 136(Pt 1):43-64.
- Arnould A, Dromer E, Rochat L, Van der Linden M, Azouvi P. Neurobehavioral and self-awareness changes after traumatic brain injury: Towards new multidimensional approaches. *Ann Phys Rehabil Med*. 2016 Feb;59(1):18-22.
- Granacher RP. *Traumatic Brain Injury: Methods for Clinical and Forensic Neuropsychiatric Assessment*. Second Edition. Ed. CRC Press. 2008.
- Walker KR, Tesco G. Molecular mechanisms of cognitive dysfunction following traumatic brain injury. *Front Aging Neurosci*. 2013 Jul 9;5:29.
- Zollman FS. *Manual of Traumatic Brain Injury Management*. First edition. Demos Medical Publishing. 2011.
- Silver JM, McAllister TW, Yudofsky SC. *Textbook of Traumatic Brain Injury*, Second Edition, American Psychiatric Publishing, Washington DC. 2011.
- Cowe SF. *The Behavioural and Emotional Complications of Traumatic Brain Injury*. First edition. Taylor & Francis Group. 2008.
- Handelman M, Parke B. The Beneficial Role of a Judicial Process When "Everything" Is Too Much?. *Healthc Q*. 2008;11(4):46-50.
- Pape TL, Jaffe NO, Savage T, Collins E, Warden D. Unresolved legal and ethical issues in research of adults with severe traumatic brain injury: Analysis of an ongoing protocol. *J Rehabil Res Dev*. 2004 Mar;41(2):155-74.
- Cancelliere A. *Cognitive, Emotional And Behavioural Changes Following Traumatic Brain Injury: Mechanisms And Management*. The Ontario Brain Injury Association. 2011
- Zolman FS. *Manual of Traumatic Brain Injury Management*. Demos Medical Publishing. New York. 2011.
- Stern RA, Riley DO, Daneshvar DH, Cantu RC, McKee AC. Long-term Consequences of Repetitive Brain Trauma: Chronic Traumatic Encephalopathy. *PM R* 2011; 3: S460-S467.
- Green DS, MacKenzie CR. Nuances of Informed Consent: The Paradigm of Regional Anesthesia. *HSSJ* (2007) 3: 115–118. World Medical Association. *Medical Ethics Manual*. 3rd edition, 2015.
- Howe LLS. Distinguishing genuine from malingered posttraumatic stress disorder in head injury litigation. *Detection of Malingering during Head Injury Litigation*. 2012, 301-331, DOI: 10.1007/978-1-4614-0442-2_11.